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ABSTRACT

The annotated bibliography describes resources covering a wide range of issues related to disabled youth and their families. The 38 bibliographic citations date from 1980 to 1989 and are grouped into the following categories: psychosocial issues, health issues, educational issues, and community living. Information is also provided on services of the National Center for Youth with Disabilities as well as addresses and phone numbers of six other information sources on youth with disabilities. (DB)

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National Center for Youth with Disabilities

. . . a resource center to improve services for youth with disabilities.

CYDLINE Reviews:

An Introduction to Youth with Disabilities Annotated Bibliography

February, 1990

A collaborative project of the:

Society for Adolescent Medicine
Adolescent Health Program

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The National Center for Youth with Disabilities is a collaborative project of the Society for Adolescent Medicine and the Adolescent Health Program at the University of Minnesota. The Center is supported through a grant from the Bureau of Maternal and Child Health and Resources Development, Division of Services for Children with Special Health Needs, Department of Health and Human Services, #MCJ27361-010. The Center's mission is to raise awareness of the needs of youth with disabilities; foster coordination and collaboration among agencies, professionals, parents, and youth in planning and providing services; and provide technical assistance and consultation.

For additional information on the Society for Adolescent Medicine, contact:

Society for Adolescent Medicine
10727 White Oak Avenue
Suite 101
Granada Hills, CA 91344
818/368-5996

For additional information on the National Center for Youth with Disabilities, contact:

National Center for Youth with Disabilities
Box 721 UMHC
Harvard Street at East River Road
Minneapolis, MN 55455
1-800-333-6293 or 612/626-2825

National
Center for

Youth with Disabilities

The National Center for Youth with Disabilities (NCYD) is committed to raising awareness of the needs of adolescents and young adults with chronic illnesses and disabilities. In keeping with this mission, we have prepared this bibliography covering a wide range of issues related to youth and their families. This is one in an ongoing series of NCYD annotated bibliographies—others include topics such as the transition from pediatric to adult health care, issues related to chronic illness for school personnel, decision-making for youth, and drug abuse. We hope that you will take the time to read through this bibliography and share it with anyone you believe would benefit from the information.

The information in this bibliography is drawn from the computerized database of the NCYD Resource Library. Contained in the Resource Library is information on journal articles, books, and unpublished documents; training materials such as videos and curricula; and information on model programs that can be used for planning purposes. A Technical Assistance Network of individuals with expertise on diverse youth- and disability-related issues is available to provide technical assistance and consulting. Additionally, the Resource Library offers access to information on federal and state case law and legislation related to youth with disabilities across many service sectors.

You can request specialized searches of the NCYD Resource Library on topics of your choosing simply by calling an NCYD information specialist. This person will then send you the requested information in a format similar to this bibliography. The minimum charge for this service is $5.00. The database is also directly accessible, through menus or a command system, for interested individuals with their own computer and modem. The basic charge for this direct access method is $25.00 per hour with an $11.00 minimum use charge; the user pays any long distance charges. Either way, you can easily receive current information on youth with disabilities that is specific to your particular needs and interests.

Thank you for your interest in the National Center for Youth with Disabilities. If you would like additional information on our Center, or would like to request information about the Resource Library, please call our information specialist toll-free at 1-800-333-6293.

I. PSYCHOSOCIAL ISSUES

AUTHOR Cowardin NW;
TITLE **Adolescent characteristics associated with acceptance of handicapped peers.**
SOURCE *Adolescence* 1986 Winter; 21(84): 931-40;
ABSTRACT Using the Peer Acceptance Scale, data were collected from nonhandicapped students. The acceptance exhibited by these students was found to be correlated with: gender, ethnicity, chronological age, school achievement, moral development, popularity, and overall peer acceptance. No relation was found between acceptance and: socioeconomic status, physical ability, and length of acquaintance. Implications are discussed. The referrent students had learning disabilities or mental retardation.

AUTHOR Kellerman J; Zeltzer L; Ellenberg L; et al.;
TITLE **Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control.**
SOURCE *J Pediatr* 1980 Jul; 97(1): 126-131;
ABSTRACT Comparison of 349 healthy adolescents and 168 with chronic diseases, indicating psychologic normalcy and realistic perceptions in most patients.

AUTHOR Orr DP; Weller SC; Satterwhite B; et al.;
TITLE **Psychosocial implications of chronic illness in adolescence.**
SOURCE *J Pediatr* 1984 Jan; 104(1): 152-7;
ABSTRACT This is an eight-year follow-up of children with a chronic illness. Health status at follow-up correlated with eight psychosocial variables: planning for the future, engaging in family activities, dating, possession of a driver's license, talking with parents, satisfaction with family life, school enrollment and school adjustment. While most of the adolescents with chronic illness showed normal adjustment, those who experienced a resulting impairment were most at risk for problems in the above areas.

AUTHOR Brier N;
TITLE **The mildly retarded adolescent: A psychosocial perspective.**
SOURCE *J Dev Behav Pediatr* 1986 Oct; 7(5): 320-3;
ABSTRACT Discussion of developmental issues, guidelines for counseling and support.

AUTHOR Kashani JH;
TITLE **Self-esteem of handicapped children and adolescents.**
SOURCE *Dev Med Child Neurol* 1986 Feb; 28(1): 81-3;
ABSTRACT A general discussion of approaches to meeting the psychosocial needs of handicapped children and adolescents. Particular attention is given to the roles played by the handicapped individual, his/her peers, family, and clinicians. These actors all contribute to the child's self-image, and they often interact. It is pointed out that the psychosocial effects of a physical handicap are most often a function of the input of the people surrounding the affected individual.

AUTHOR Woodhead JC; Murph JR;
TITLE **Influence of chronic illness and disability on adolescent sexual development.**
SOURCE *Semin Adol Med* 1985 Sep; 1(3): 171-6;
ABSTRACT Discussion of sexual issues with a psychosocial emphasis as relating to chronic illness and disability by developmental level.

AUTHOR Elkind D;
TITLE **Cognitive development and adolescent disabilities.**
SOURCE *J Adol Health Care* 1985 Mar; 6(2): 84-9;
ABSTRACT Discusses adolescent cognitive development as it interacts with chronic disabilities, exacerbating existing conditions and contributing to the etiology of new problems. Gives suggestions for working with cognitive constructs.

AUTHOR Blum RW;
TITLE **Developing with disabilities: The early adolescent experience.**
BOOK Early Adolescent Transitions
EDITOR Levine MD; McAnarney ER;
SOURCE Lexington Books: Lexington, MA, 1988: 177-92;
ABSTRACT Discussion of normal early adolescent development and its adaptations in youth with chronic illness or disabilities.

AUTHOR Strax T; Wolfson S;
TITLE **Life-cycle crisis of the disabled adolescent and young adult: Implications for public policy.**
BOOK Chronic Illness and Disabilities in Childhood and Adolescence.
EDITOR Blum RW;
SOURCE Grune and Stratton: NY, 1984: 47-57;

II. HEALTH ISSUES

AUTHOR Siegel DM;
TITLE **Adolescents and chronic illness.**
SOURCE *JAMA* 1987 Jun; 257(24): 3396-9;
ABSTRACT Epidemiologic background including prevalence data for 21 major chronic disorders: arthritis, asthma, autism, CNS injury, cerebral palsy, chronic renal failure, cleft lip/palate, congenital heart disease, cystic fibrosis, diabetes mellitus, Down syndrome, hearing impairment, hemophilia, leukemia, mental retardation, muscular dystrophy, spina bifida, PKU, sickle cell disease, seizure disorder, and visual impairments. The impact of chronic illness on normal adolescent development is discussed. Organization of health care and the adolescent's access to that care is examined.

AUTHOR Batshaw ML; Perret YM;
TITLE **Children with Handicaps - A Medical Primer.**
SOURCE Paul H. Brookes:Baltimore,1986:473;
ABSTRACT Written in language appropriate for educators, this comprehensive text regarding medical aspects of children and youth with handicapping conditions provides in-depth studies of particular conditions. More than 130 detailed illustrations and a glossary are included.

AUTHOR Buhlmann U; Fitzpatrick SB;
TITLE **Caring for an adolescent with a chronic illness.**
SOURCE *Prim Care* 1987 Mar; 14(1): 57-68;
ABSTRACT Review of the impact of chronic disease on adolescent development. Issues related to the adolescent's family, hospitalization, and dying are discussed. Early-, mid-, and late-adolescence are specifically addressed. Many case examples are used to illustrate concepts. Implications for the primary care physician are suggested.

AUTHOR Story M;
TITLE **Nutritional needs of adolescents with chronic and handicapping conditions.**
BOOK Chronic Illness and Disabilities in Childhood and Adolescence.
EDITOR Blum RW;
SOURCE Grune and Stratton: NY, 1984: 97-126;

AUTHOR Bush EG; Magyar PH;
TITLE **Conflicting claims: An ethical dilemma in family-centered care.**
SOURCE *J Assoc Pediatr Oncol Nurses* 1986; 3(3): 9-12, 27;
ABSTRACT Through the example of a single case study, this article describes ethical nursing approaches to interpersonal conflict in cancer care decision making. Adolescent development is taken into account. The dilemma described is disagreement on treatment continuation between an adolescent patient and her family and physician. Approaches discussed include: utilitarian or goal-based, deontological or duty-based, and rights-based or advocacy approach.

AUTHOR Faigel HC;
TITLE **Providing for students with physical disabilities: The role of a student health service.**
SOURCE *Int J Adolesc Med Health* 1987 Jan; 3(1): 5-12;
ABSTRACT The need for coordinated care which is responsive to their academic and social needs as well as to the students' physical handicap is imperative. A student health center can provide health services as well as coordination of care.

AUTHOR Blum RW;
TITLE **Compliance in the adolescent with chronic illness.**
SOURCE *Semin Adol Med* 1987 Jun; 3(2): 157-62;
ABSTRACT This article discusses a multidimensional model of compliance behavior, the measurement of compliance, factors influencing compliance, and suggestions for enhancing compliance.

AUTHOR Brunswick AF;
TITLE **Health services for adolescents with impairment, disability and/or handicap: An ecological paradigm.**
SOURCE *J Adol Health Care* 1985 Mar; 6(2): 141-51;
ABSTRACT The author functionally defines adolescent disability and proposes a framework to guide the selection of services for a community health program. She also formulates a set of guidelines that could be used to evaluate health services for disabled adolescents.

AUTHOR Paxman JM;
TITLE **Health care for handicapped adolescents: International legislative and policy trends.**
SOURCE *J Adol Health Care* 1982 Sep; 3(2): 103-9;
ABSTRACT Discussion of international legislative supports, definitions of "handicap", comprehensive health care programs, prevention, detection and reporting systems, treatment and rehabilitation programs, and complementary forms of assistance for handicaps.

III. EDUCATIONAL ISSUES

AUTHOR Radencich MC;
TITLE **Literature for minority handicapped students.**
SOURCE *Reading Res Instr* 1986 Summer; 25(4): 288-94;
ABSTRACT This article cites literature that is particulary relevant to students who are both minorities as well as handicapped. The collection of materials addresses needs specifically pertinent to this group of youth. The books are targeted for individuals with handicapps and to their families, peers and teachers.

AUTHOR Fox AM;
TITLE **Special educational needs of the physically disabled child and adolescent.**
SOURCE *Pediatrician* 1986; 13(2-3): 133-40;
ABSTRACT This discussion focuses on educational approaches to reducing handicaps (social and environmental). Specific issues addressed include: behavioral sequelae of physical disability; attitudes toward disabilities in schools; mainstreaming, access/mobility; the classroom environment; technological aids; the role of the physical, occupational, and speech therapist; the need for special education; and adolescence.

AUTHOR Johnson DR; Bruininks RH; Thurlow ML;
TITLE **Meeting the challenge of transition service planning through improved interagency cooperation.**
SOURCE *Except Child* 1987 Apr; 53(6): 522-530;
ABSTRACT This article describes the importance of effective management strategies when planning and coordinating for transition. Barriers to transition planning are discussed and suggestions are made to reduce these barriers: 1) Develop a consistent policy framework; 2) Employ effective management practices to meet policy goals; 3) Collect valid, reliable information on which to base goals and guide decision making; and 4) evaluate outcomes, including costs and benefits, to use as a basis for policy decisions.

AUTHOR Rothstein LF;
TITLE **Section 504 of the Rehabilitation Act: Emerging issues for colleges and universities.**
SOURCE *J College Univ Law* 1986 Winter; 13(3): 229-65;
ABSTRACT Review of judicial and regulatory developments in relation to colleges' and universities' compliance with section 504 of the Rehabilitation Act.

AUTHOR Jenkins AE; Amos OC; Graham GT;
TITLE **Do Black and white college students with disabilities view their worlds differently?**
SOURCE *J Rehabil* 1988 Jul; 54(3): 71-6;
ABSTRACT Findings indicate that the two groups do not view their worlds in significantly different ways. Responses to questions about family relationships, human services, and feelings about self were very similar.

IV. COMMUNITY LIVING

AUTHOR Wehman P; Wood W; Everson JM; et al;
BOOK **Vocational Education for Multihandicapped Youth with Cerebral Palsy.**
SOURCE Paul H. Brookes: Baltimore, 1988: 256;
ABSTRACT Resource for vocational educators' use in developing a curriculum to meet the needs of individual students with cerebral palsy. Formats for teaching vocational skills, resources for adaptation, and rehabilitation engineering technology are detailed. A program for beginning a community-based work program and transition process is included.

AUTHOR Hill M; Wehman P;
TITLE **Cost benefit analysis of placing moderately and severely handicapped individuals into competitive employment.**
SOURCE *JASH* 1983 Spring; 8(1): 30-38;
ABSTRACT This article introduces an analysis of total costs accumulated and tax monies saved, over a 4-year period, through the successful implementation and maintenance of a job training and placement program for moderately and severely handicapped workers. Relevant factors include the number of months the client worked, amount of staff hours needed, funds spent proportionately on each client, SSI saved, estimated cost of day programming for the client if no job placement had been made and tax credit. The focus of the analysis is on the money saved rather than the wages earned by the moderately and severely handicapped workers.

EDITOR Hobbs N; Perrin JM;
BOOK **Issues in the Care of Children with Chronic Illness.**
SOURCE Jossey-Bass: San Francisco, 1985: 953;
ABSTRACT A major text in the field including discussions of basic concepts of chronic illness; epidemiology, demography, and representative conditions; populations with special needs; provision of services and professional training; educational and vocational issues; programs and organizations serving chronically ill children and their families; and economic considerations. 42 chapters.

EDITOR Wallace HM; Biehl RF; Oglesby AC; et al;
BOOK **Handicapped Children and Youth. A Comprehensive Community and Clinical Approach.**
SOURCE Human Sciences Press: New York, 1987: 378;
ABSTRACT Professionals from many disciplines contributed to this text designed for a broad audience of professionals. The first chapters describe definitions of disability, the impact on children and families, historical approaches to services, and current services within public programs and voluntary organizations. Subsequent chapters address legal rights, advocacy, early identification and screening, evaluation and management, nutritional needs, oral health, the role of various professionals, special education, sexuality, respite care, transportation, and state and community programs. The last third of the book includes overviews of many handicapping conditions. This could be a useful introductory text for students in many disciplines who will deal with children with disabilities.

AUTHOR MacLead RJ; Parker Z;
TITLE **Considerations in community mental health programming for youth.**
SOURCE *Can J Psychiatry* 1986 Aug; 31(6): 568-74;
ABSTRACT Principles for developing a comprehensive integrated multiservice center with effective community liaison.

AUTHOR Weiss G; Hechtman LT;
BOOK **Hyperactive Children Grown Up. Empirical Findings and Theoretical Considerations.**
SOURCE Guilford Press: New York, 1986: 367;
ABSTRACT The authors summarize studies conducted at McGill University since 1961 following children and adolescents with hyperactivity/attention deficit disorder into adulthood. They examine many factors which may predict the clinical presentation, impact on psychosocial functioning and outcome, citing case examples.

AUTHOR Watts WJ;
TITLE **What does the future hold in store for the learning-disabled adolescent?**
SOURCE *Int J Adolesc Med Health* 1986 Oct; 2(4): 253-270;
ABSTRACT Article presents and discusses various characteristics of the LD adolescent and adult; academic, intellectual and vocational prospects; attempts to identify and improve social skills; and summaries of longitudinal follow-up studies of adjustment of adolescents with learning disabilities.

BOOK **The Right to Grow Up: An Introduction to Adults with Developmental Disabilities.**
EDITOR Summers JA;
SOURCE Paul H. Brookes:Baltimore, 1986: 352;
ABSTRACT Provides a sensitive appraisal of the changing emotional and physical needs of maturing young adults and offers means to evaluate quality of life, level of personal benefit and degree of freedom offered by any service program.

BOOK **The Young Person with Down Syndrome - Transition from Adolescence to Adulthood.**
EDITOR Pueschel SM;
SOURCE Paul H. Brookes: Baltimore, 1988: 256;
ABSTRACT Discussion of critical issues surrounding transition to adult life around the following areas: independent living, sex and marriage, self-awareness and esteem, employment, recreation, social integration. Describes innovative programs and practical strategies to address transition process.

AUTHOR Turnbull HR; Turnbull AP; Bronicki GJ; et al;
BOOK **Disability and the Family: A Guide to Decisions for Adulthood.**
SOURCE Paul H Brookes:Baltimore, 1989: 432;
ABSTRACT Practical information and steps for planning for the future of adolescents with disabilities. Includes legal, social-interpersonal, vocational and residential options. Methods for self-assessment, self-advocacy, and lists of resources to assist in planning are included.

AUTHOR Gould M;
TITLE **Self-advocacy: Consumer leadership for the transition years.**
SOURCE *J Rehabil* 1986 Oct; 52(4): 39-42;
ABSTRACT This article describes and examines current conceptual frameworks and contemporary thinking about transitional issues. An analysis and discussion of self-advocacy, one missing element in recent transition models and program service efforts, is presented. Options and recommendations for including self-advocacy in service program models are also offered.

BOOK **Community-Based Living Options for Young Adults with Deaf-Blindness: Philosophy, Directions, and Strategies.**
EDITOR Barrett SS; Carr TS; Covert AM;
SOURCE Helen Keller National Center: 1987;
ABSTRACT A primer on an array of issues that affect the choice of community living options for young adults with deaf-blindness.

AUTHOR Margolin KN;
TITLE **Risks of a privacy policy by residential institutions for handicapped adolescents.**
SOURCE *J Rehabil* 1988 Apr; 54(2): 50-54;
ABSTRACT Two hundred professionals met to discuss sexual exploration and expression by handicapped youth living in residential facilities. This article considers the legal implications for institutions deciding to provide privacy for its older handicapped youth and provides practical suggestions as to how such a policy can best be started.

AUTHOR McManus MA;
BOOK **Understanding Your Health Insurance Options: A Guide for Families Who Have Children With Special Health Care Needs.**
SOURCE McManus Health Policy, Inc.:4801 Massachusetts Avenue NW, Suite 400, Washington, D.C. 20016 (202) 895-1580, 1988: 30;
ABSTRACT An insurance guide which details public and private insurance options, including: Medicaid, Title V, traditional plans, HMO's, and preferred provider organizations. This "how-to" pamphlet provides answers to commonly asked questions, worksheets for comparing options, and suggestions on how to choose appropriate insurance coverage. A glossary of terms is also provided.

AUTHOR Schleien SJ; Ray MT;
BOOK **Community Recreation and Persons with Disabilities.**
SOURCE Paul H. Brookes: Baltimore MD, 1988: 288;
ABSTRACT Comprehensive practical guide focuses on a systems change approach for an integrated system of recreational/leisure programs. Contains a plan for creating opportunities applying behavior analysis to problems in working with some individuals, lists six exemplary programs and provides an annotated bibliography.

OTHER INFORMATION SOURCES ON YOUTH WITH DISABILITIES

HEATH Resource Center
(Higher Education and Adult Training for People with Handicaps)
One Dupont Circle, N.W.
Suite 800
Washington, D.C. 20036-1193
1-800-544-3284

NICHCY
(National Information Center for Handicapped Children and Youth)
PO Box 1492
Washington, D.C. 20013
1-800-999-5599

National Health Information Center
PO Box 1133
Washington, D.C. 20013-1133
1-800-336-4797

ERIC Clearinghouse on Handicapped and Gifted Children
Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
703/620-3660

National Rehabilitation Information Center
8455 Colesville Road
Suite 935
Silver Spring, MD 20910
1-800-346-2742

National Maternal and Child Health Clearinghouse
38 and "R" Streets, N.W.
Washington, D.C. 20057
202/625-8410

CYDLINE Reviews

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